

Episode: *Author Interview: “How Innovative Designs Can Help Ease Ethical Tension in Good Dementia Caregiving and Decision-Making”*

Guest: Emily Roberts, PhD

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Transcript: Cheryl Green

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[bright theme music]

[00:00:03] TIM HOFF: Welcome to another episode of the Author Interview series from the *American Medical Association Journal of Ethics*. I'm your host, Tim Hoff. This series provides an alternative way to access the interesting and important work being done by Journal contributors each month. Joining me on this episode is Dr Emily Roberts, an associate professor at Oklahoma State University in Stillwater, Oklahoma, with backgrounds in design and gerontology. She's here to discuss her article, “*How Innovative Designs Can Help Ease Ethical Tension in Good Dementia Caregiving and Decision-Making*,” in the December 2024 issue of the Journal, [Evidence-Based Design in Health Care](#). Dr Roberts, thank you so much for being here.

DR EMILY ROBERTS: Thank you. So happy to be here with you. [music fades]

[00:00:48] HOFF: So, what is the main ethics point of your article?

ROBERTS: Well, thanks for the question. What we've been seeing is that evolving pressures in contemporary US cities include density, affordability, and the need for strengthening of community. And for individuals with dementia and their families, the burden of living with dementia in this context can be overwhelming. Once family caregivers no longer feel confident in their caregiving role, the individual with dementia may be institutionalized, leading to many negative outcomes, being further connected from home, family, community, and meaningful activities. Activities stimulate a sense of wellbeing, create a sense of personal fulfillment, and promote both physical and mental health, creating daily meaning. And although it's imperative that vulnerable populations are provided care settings which allow for personal fulfillment, memory care settings more often are known as places of isolation and depression.

In biomedical terms, dementia is seen as a syndrome produced by diseases such as Alzheimer's, Parkinson's, and vascular dementia, with a cluster of symptoms linked to the deterioration of cognitive abilities. People living with dementia may need help with their daily activities while making the most of their present strengths. It's estimated that about 5.4 million Americans have some form of dementia, and these numbers will continue to escalate. As the number of older Americans grow, so too will the number of new cases of dementia. This manuscript addresses the ethics of past and future memory care models, looking specifically at existing European dementia village models, and a new proposed dementia-friendly city center model, both which negotiate rivaling discourses of risk and autonomy.

[00:02:31] The first dementia village in the Netherlands has been operated with the mindset of humanizing care while providing a normal life to residents. It's designed as a traditional Dutch neighborhood with housing, along with opportunities for residents to wander freely while taking part in programs and activities throughout the village, such as shopping at a supermarket, viewing art exhibitions, attending concerts, and dining in restaurants and cafes. The four-acre site was purposely designed to maximize resident autonomy while maximizing safety concerns as well. Nearly 50 percent of the site is outdoors, including gardens, seating, bike paths designed by several landscape architects, who each designed a different, unique courtyard to differentiate the walking experience for residents.

Referring to that dementia village model as a precedent, in 2017, our research team began to look for new ways of addressing the needs of those living with dementia in our community. In searching for innovative options, repurposing existing structures—in particular, vacant urban malls—was identified as an option for the large sites needed for the European model of dementia villages. These settings were identified as dementia-friendly city centers because in the case of existing mall construction, the internal infrastructure's already in place with varied spatial configurations of public spaces, and along with purpose-built attached housing, become a setting which can enhance autonomy in the daily lives of residents.

[00:03:58] HOFF: So, what should health professions students and trainees be taking from this article specifically?

ROBERTS: Well, as we look forward in ethical care for individuals who need extra support, it's imperative that as a society, we start to flip the ageist perspective of "us/them" to the notion of "we" in care policy. From the inception of the first dementia village in 2009, there was a shared vision and mutual understanding of the goals among its founders and stakeholders. This highlights the importance of bringing together stakeholders who share the desire to create an environment which will be a nice place to live, with or without dementia. We're beginning to understand that current and future generations of older adults will not accept living in an environment in which they do not have choice as how to spend their days.

We find that viewing individuals with dementia as patients who must be kept safe at all costs is not realistic. Yet our cultural norms tell us that if you age without a diagnosis of dementia, then you can live with any risk you want. You can go bungee jumping or skydiving. Think George Bush Sr. But if you have a dementia diagnosis, often it may seem that everything stops around you. This may be society's biggest ethical challenge: not to see people living with dementia as patients, but just as people who have a set of needs requiring different types of support to live with those needs. So if you can ask yourself the question, what options would I like to see in my future environment with or without dementia, this is a good way to begin the conversation about the ethics of dementia care.

[00:05:36] HOFF: And finally, if you could add a point to this article, what would that be?

ROBERTS: Well, I think it's often problematic to introduce an innovative idea without an understandable precedent or prototype. The nexus of the evidence-based ethical approach addresses the abilities residents still have and want to keep, and is focused on patterns of living rather than just the care of the individual's needs. In essence, there's an understanding that there is quality in days and is the individual's choice how they want to spend those days. This positive health approach allows for resident resilience in a setting where they can strengthen their abilities and not mourn what abilities they may have lost. This is the distinction between this approach rather than a clinical approach. While there is clinical care and support when needed, social needs in these models are addressed on a daily basis within the housing, as well as the ongoing activities and social clubs. And really, that's one of the most striking outcomes of the model. For instance, on a sunny day that I visited the dementia village, residents were socializing outside, whether strolling, sitting in the outdoor cafe, or spending time with family. People are people. They're human beings. [theme music returns] And we can see that the creation of care settings where people can live with different care needs with the necessary support is an ethical, viable goal.

[00:07:00] HOFF: Dr Roberts, thank you so much for your time on the podcast today, and thanks for your contribution to the Journal this month.

ROBERTS: Thank you so much. I appreciate it.

HOFF: To read the full article, as well as the rest of this month's issue for free, visit our site, journalofethics.org. We'll be back soon with more *Ethics Talk* from the *American Medical Association Journal of Ethics*.